Comments of Access Living on improvements to the Medicaid program
For the Governor's Health Reform Implementation Council

Access Living is a nonprofit, nonresidential Center for Independent Living in Chicago, devoted to fostering independent lifestyles, supporting self-determination, and facilitating full community integration of people with disabilities in the Chicago metropolitan area. Governed and staffed by a majority of people with disabilities, Access Living strongly advocates for and promotes community-based, consumer-controlled services and programs and the right of people with disabilities to make their own decisions about quality-of-life issues, including health care.

Pointing out the greatly expanded reach of Medicaid in Illinois after 2014, this Council has posed the question, "What changes would improve the Medicaid Program?" The disability community would be greatly benefited by improvements in two areas: (1) strategies and mechanisms to build into Medicaid improved compliance with the Americans with Disabilities Act in the area of health care access and (2) partnering with and inclusion of persons with disabilities and their advocates in the design, development, and oversight of the Medicaid programs that serve them. While Access Living does not endorse managed care as an optimal service delivery system, it does recognize that the new pilot project engaging Medicaid managed care organizations (MCOs) will provide five years of federal funds and a unique opportunity to take significant steps to implement both of these improvements.

(1) ADA Enforcement

Two primary goals of the Americans with Disabilities Act (ADA) were to provide persons with disabilities full inclusion in the services and benefits available to others and the same opportunities for control over choices in their lives. Certainly, access to healthcare is an essential benefit to a population that needs and uses healthcare services at a higher rate than persons without disabilities.

Over twelve years ago, the U.S. Department of Health and Human Services issued a document entitled "Key Approaches to the Use of Managed Care Systems for Persons with Special Health Care Needs," recommending ADA compliance mechanisms including (1) use of informational materials accessible to persons with sight or hearing impairments, (2) providers trained in an expert level of care for persons with special health care needs, and (3) "compliance with all relevant provisions of the Americans with Disabilities Act, along with other relevant Federal statutes, in relation to the development of care delivery systems for persons with special health care needs." http://library.findlaw.com/1998/Oct/8/130735.html

Yet, twenty years after the passage of the ADA and twelve years after issuance of the HHS document, persons with disabilities still experience health care disparities and routinely encounter a wide range of obstacles to healthcare access, including architectural barriers, inside and outside, inadequately sized examination rooms, inaccessible examination tables, inaccessible medical equipment for screening, diagnosis, and treatment, the absence of auxiliary communication aids and services, poor training of providers in disability-related health issues, and negative preconceptions about persons with disabilities that hinder comprehensive care. Reis, J.P., Breslin, M.L., Iezzoni, L.I., Kirschner, K.L., "It Takes More Than Ramps" (Rehabilitation Institute of Chicago 2004), http://www.ric.org/pdf/RIC_whitepaperfinal82704.pdf

To be sure, Department of Justice lawsuits resulting in settlements and consent decrees since passage of the ADA have produced comprehensive improvements in some individual health care centers and other facilities. But these cases also demonstrate how intractable the problems in health care access continue to be – and litigation is slow, cumbersome, and limited in its results. What is needed is not change in healthcare delivery one health care center at a time, but rather systemic reform and strategies for enforcement of ADA standards that make accessible healthcare a reality for persons with disabilities.

Federal authorities have taken substantial steps toward systemic change in health care access. A prominent example is the requirement in the Affordable Care Act that the United States Access Board, in consultation with the FDA, develop minimum technical criteria by early 2012 for medical diagnostic equipment to assure accessibility of such equipment to individuals with accessibility needs. However, federal guidelines and standards only go so far. ***In the end, it is the responsibility of the State of Illinois to assure that its Medicaid providers comply with federal law, including the ADA.***

Access Living recommends as a model for the implementation of ADA compliant Medicaid providers New York's 1997 "Guidelines for Medicaid MCO Compliance with the ADA," http://www.health.state.ny.us/health_care/managed_care/pdf/appendixj.pdf. The New York Guidelines include accessibility standards to *qualify* MCOs for participation in the New York Medicaid Managed Care Program. The Guidelines are comprehensive in scope, covering environmental accessibility, nondiscrimination in policies and procedures, and accommodations. New York, recognizing *its own responsibility* to assure program access to all recipients, mandates each MCO to submit an ADA Compliance Plan describing in detail how the MCO will make its services, programs, and activities readily accessible to individuals with disabilities and, in the event some sites are not readily accessible, to describe reasonable alternative methods for making services or activities accessible.

The success of the New York compliance standards is reflected in the 2005 compliance plan filed by "Health Plus," a plan providing publicly funded healthcare services. http://www.healthplus-ny.org/data/HP_ADA_Plan_2005-revisions.pdf That plan includes, but is not limited to, physical and environmental accessibility for all services, ADA and disability awareness training for all Health Plus employees, interpreters proficient in American Sign Language, materials in alternative formats for persons with visual impairments, staff trained to

read aloud and explain health materials to persons with cognitive impairments, trained advocates for persons with disabilities, provider training on common secondary conditions affecting persons with disabilities, workshops on health promotion for persons with disabilities, assistance with transportation arrangements, assistance to persons with disabilities in filing complaints and appeals, case managers for persons with severe disabilities requiring specialized care, and availability of out-of-network providers when medically necessary care cannot be obtained in-network. Rather than break the back of Health Plus, implementation of these these reforms resulted in a quality rating so high that the plan was awarded an extra 1.5% in Medicaid premiums in 2008, translating to an additional $6 million in annual funding. http://www.healthplus-ny.org/en/79_ENG_HTML.html

New York is only one example of a state that has devised ADA compliance strategies for Medicaid providers, but it demonstrates that such strategies can be implemented successfully and profitably. Access Living recommends that Illinois take its place among forward-thinking States that assure that Medicaid reform efforts include ADA implementation strategies. Specifically, Access Living's Health Access Policy Analyst Judy Panko Reis and Community Health Representative Tom Wilson have proposed the following performance standards for Illinois managed care organizations serving people with disabilities and chronic conditions:

- That all Medicaid MCOs selected by the State of Illinois provide healthcare services compliant with the requirements of the ADA and the expansion of those requirements by the Department of Justice Healthcare Access Guidelines;
- That a State ADA Coordinator be appointed to oversee the design and implementation of MCOs' ADA plan, to include a consumer appeals process and ADA hotline for consumers, and that an ADA Liaison be required for each Medicaid MCO to assist in creating the organization's compliance plan and in educating the MCO's consumers;
- That out-of-network services be accommodated when in-network services are not ADA compliant; and
- That Medicaid MCOs assure access to disability-specific specialized services in rehabilitation, allied health services, and seating-positioning and assistive technology.

A full copy of these proposed performance standards is appended hereto.

(2) Consumer Involvement

Dr. Robert J. Master's Commonwealth Care Alliance is an innovative publicly financed health care system in Boston for low-income older adults with chronic illnesses and complex medical conditions. http://commonhealth.wbur.org/. Focusing on the unique, individual needs of patients and a preventive rapid response to those needs, Dr. Master's system has so drastically reduced costly emergency room visits, hospital admissions, and hospital length of stays that the plan generated in 2008 a $3.24 surplus that was reinvested in primary care enhancements above what Medicare would have paid. http://commonhealth.wbur.org/ An affiliate of Commonwealth Care Alliance, Boston Community Medical Group (BCMG), provides community-based primary care to individuals with neurological disabilities who experience mobility impairment and rely on personal care attendants. BCMG won an award in February 2010 for its exemplary efforts to improve access to healthcare for underserved populations.
http://www.commonwealthcare.org/downloads/Release_BCMG_2.9.10.pdf

Commonwealth Care Alliance evolved from Dr. Master's previous innovation, an experimental program called Community Medical Alliance serving Medicaid-financed care for individuals with advanced AIDS and severe disability. Dr. Master saw his role as "redesign[ing] the delivery system so that it was attuned to the populations." Master, R.J., "Massachusetts Medicaid and the Community Medical Alliance," American Journal of Managed Care, Vol. 4, June 25, 1998, p. SP91. Dr. Master stated that, in formulating that redesign, he avoided costly "expert" professionals and instead consulted with "those with intimate knowledge of a specific disability" – the consumers themselves, working collaboratively with Boston's Center for Independent Living. *Id.*, pp. SP 92-93. The brochure for Commonwealth Care Alliance states:

> Years of experience has taught us that individuals with chronic illness know better than anyone else what works and what doesn't work when it comes to the care they need. Meaningful consumer involvement is central to Commonwealth Care Alliance. In fact, we are organized as a "consumer-governed care system" to ensure that the consumer's voice is built in to all aspects of our activities.

http://www.commonwealthcare.org/downloads/CCA%20brochure_English.pdf. Consumer organizations are included as corporate members, and the first factor that Dr. Master lists as an element for a successful care model for special needs patients is "meaningful consumer involvement in care management and care design." (p. 10) Master, R.J., "Improving Care and Managing Costs for Dually Eligible, Elderly and Disabled Populations," p. 10, http://aspe.hhs.gov/medicaid/may/Dr.RobertMaster.pdf.

Dr. Master is by no means alone in his observations about consumer involvement. John Barth, senior program officer at the Center for Health Care Strategies, authored a 2007 article about the experience of several states in engaging consumers in the design, implementation, and oversight of Medicaid managed care. Mr. Barth found that the critical strategy for the success of such programs with respect to the needs of persons with disabilities was *building consumer support by partnering with consumer representatives* from the inception. Examples of successful strategies include Indiana's use of regional public meetings to gather information and opinions from consumer and advocacy communities, New York's use of focus groups to gather refined feedback on specific program design and operational questions, Wisconsin's use of advisory committees that include persons with disabilities, Pennsylvania's use of oversight committees that include consumer and advocacy group representatives who are permitted to review and analyze program data and develop consumer education and outreach materials, and Ohio's use of websites to share information with consumers and provide a conduit for feedback. http://www.chcs.org/usr_doc/Consumer_Voice_Issue_Brief.pdf. Federal law mandates the establishment of Medicaid Medical Care Advisory Committees (MCACs) and their inclusion of consumer group representatives, Medicaid recipients, and other consumer-oriented organizations, and exemplary state MCAC operations have proven invaluable in enlisting consumer support and eliciting consumer wisdom. Perkins, J., and Somers, S., "Fact Sheet: Medicaid Medical Care Advisory Committees" (National Health Law Program 2005). http://www.ndrn.org/images/Documents/Issues/Medicare_Medicaid/NDRN_medcare_advisory_committees.pdf

In short, a strong consumer voice will be essential in the creation in Illinois of Medicaid MCOs capable of delivering high quality healthcare. Access Living recommends that this Coun-

cil implement meaningful avenues for people with disabilities to provide ideas, information, feedback, and advice on health program designs that serve their needs.

Finally, Access Living reminds this Council that it submitted on October 4 a position paper requesting a thorough review of the nonprofit, member-run healthcare cooperatives option contained in the Affordable Care Act and supported by $6 billion of federal funding. Fostering a strong consumer focus on accountability and the use of profits to lower premiums and improve benefits and services, these consumer-friendly arrangements free physicians to spend less time on paperwork and more time with patients, permit members to shape policy as voting members, require transparent policy-making meetings, and keep administrative costs lower than those of for-profit insurers. Replacing profit with provision of high quality healthcare will put Illinois in the lead in giving all people, including those with disabilities, the opportunity to go to a hospital or neighborhood clinic and receive competent and accessible health care.

Performance Standards for Illinois Managed Care Organizations Serving People with Disabilities and Chronic Conditions

Prepared by Access Living

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Overview

Under Titles II and III of the Americans with Disabilities Act, every healthcare provider must offer non-discriminatory healthcare services to all patients, including people with disabilities. Compliance with the ADA is essential to ensure the provision of equitable, quality healthcare for people with disabilities and chronic conditions in Illinois. It is also the law.

This issue paper outlines Access Living's recommendations for culturally competent healthcare services for those with disabilities and chronic health conditions who will soon be mandatorily enrolled in the Medicaid Managed Care Program. Access Living calls for the State of Illinois to comply with the requirements of the ADA and the Department of Justice (DOJ) Access Guidelines as they pertain to both the healthcare facilities and the delivery of services in those facilities. This paper includes a brief summary of these ADA healthcare related performance standards and recommends a set of best practices. Compiled from existing managed care programs in states across the country, these best practices aim to promote the health of consumers as well as the financial well-being of the state. Our recommendations for specific ADA oversight are modeled on similar principles implemented by the Chicago Public School System as well as the Regional Transportation Authority in the Chicago metropolitan area. In order to avoid expensive future litigation, the state should consider these best practices as measures to uphold ADA compliance.

Four Recommendations from Access Living

1. All Managed Care Organizations (MCOs) selected by the State of Illinois must provide healthcare services that comply with Titles II and III of the ADA as well as the DOJ Healthcare Access Guidelines pertaining to the ADA.

2. The State of Illinois Medicaid Managed Care Program cannot force people with disabilities and chronic conditions into a system that denies them access to ADA compliant healthcare services. The following policies must be implemented to ensure that State of Illinois MCO healthcare services are ADA compliant.

- The appointment of an ADA Coordinator to oversee the transition to managed care. In addition, each MCO should appoint an ADA Liaison to work with consumers, the insurer and the state.

- The State ADA Coordinator would oversee the design and implementation of the MCO's ADA plan, which include a consumer appeals process and an ADA hotline to address consumers ADA concerns.

- Each MCO's ADA Liaison should create a company-specific plan in collaboration with the state, the company and the consumer. The liaison will work to educate the MCO's consumers to ensure a successful transition to managed care.

3. If a selected network does not have the capacity to provide ADA-compliant healthcare services, the state must offer Medicaid Managed Care enrollees a "reasonable accommodation" by providing the option of receiving ADA-compliant services from a choice of providers outside of the network.

4. To ensure the provision of equitable, quality healthcare, disability specific services are essential. This means insurers need to recognize disability-specific healthcare needs. Persons with disabilities require greater and regular attention from specialists and greater access to specialized equipment such as motorized wheelchairs. An MCO may be motivated to decrease costs by sending a patient to a general physician when the patient urgently needs a service provided by a specialist.

   Therefore, providing access to disability-specific specialists including, but not limited to appropriative rehabilitation specialists, allied health services, seating and positioning technology and assistive technology specialists is strongly recommended. This would also be beneficial financially, since a patient's health is often adversely affected when he/she is denied appropriate, specialized care, thereby potentially costing the state more.

ADA Healthcare Related Requirements

- Title II of the ADA requires publicly funded healthcare facilities and providers to ensure their healthcare services are completely accessible to people with disabilities.

- Title III applies to all private health care providers (regardless of the size of the facility or number of employees). It requires HMOs, hospitals and healthcare facilities to remove all architectural, structural and programmatic barriers that prevent people with disabilities from accessing health care services. Physical barriers include waiting rooms, restrooms and parking spots as well as entryways. Programmatic barriers include communication accommodations such as sign language interpreters for the deaf or staff to assist in filling out forms for the blind (Reis 13-16).

- The US Department of Justice has the primary enforcement authority for enforcing the ADA. The ADA regulations can be found at www.ada.gov/reg2.html and www.ada.gov/reg3a.html.

- The most recent July 2010 updates to the ADA (available at http://www.ada.gov/medcare_mobility_ta/medcare_ta.htm) are summarized in this Fifth Freedom informational alert: "The DOJ has released a new document with guidelines for medical care accessibility. "Access to Medical Care for Individuals with Mobility Disabilities" discusses the requirements of the ADA as they relate to medical care, facilities and equipment. This document covers guidelines for things like entry doors, clear floor space & turning space, accessible exam tables & chairs, using patient lifts, transfer techniques and staff training." These updates should be considered as components of the Access Living recommendations for the State of Illinois.

Summary

This issue paper calls for the incorporation of ADA guidelines in the Medicaid Managed Care program and offers a set of best practices. If Illinois' Medicaid Managed Care program fails to address the specific health needs of people with disabilities and chronic conditions, the 40,000 enrollees will be forced into a network of inadequate providers without any chance of an opt-out. Not offering an option for out of network disability-specific care endangers the health of people with disabilities, thereby most assuredly ensuring additional costs to the state should an individual's health deteriorate. Access Living strongly recommends that the Medicaid Managed Care program ensures the provision of quality service to people with disabilities and chronic conditions by working with the disability community to identify these best practices for the state of Illinois.

Resources

Iezzoni, Lisa I., and Bonnie O'Day. *More than Ramps:A Guide to Improving Health Care Quality and Access for People with Disabilities*. Oxford: Oxford University Press, 2006. Print.

U.S. Department of Justice. "Access To Medical Care For Individuals With Mobility Disabilities." *Information and Technical Assistance on the Americans with Disabilities Act*. Web. 16 Aug. 2010. <http://www.ada.gov/medcare_mobility_ta/medcare_ta.htm>.

Reis, Judy Panko, Mary Lou Breslin, Lisa I. Iezzoni, and Kristi L. Kirschner. *It takes more than ramps to solve the crisis of healthcare for people with disabilities.* Rehabilitation Institute of Chicago, September 2004. Print. <http://www.ric.org/pdf/RIC_whitepaperfinal82704.pdf>.

Center for Healthcare Strategies, The Lewin Group, and Center for Disability Issues and the Health Professions at Western University of Health Sciences. *Medi-Cal Beneficiaries with Disabilities: Performance Standards and Measures for Managed Care.* California HealthCare Foundation, July 2008. Web. 16 Aug. 2010. <http://www.chcf.org/projects/2008/medical-beneficiaries-with-disabilities-performance-standards-and-measures-for-managed-care>.